Chapter

Useful Tools and Resources in Early Intervention Services

This chapter covers a selection of tools and resources for dementia diagnosis and management in primary care based on the experience of a community-based dementia early detection service (see Section 1.5) for use by trained allied health and social care professionals (1) and primary care physicians to promote communication across disciplines. Considering the large and growing number of validated tools available for outcome assessment and detection of dementia, our goal here is to share useful materials for quick reference rather than a comprehensive summary of available tools and resources (see Box 4.1 for some useful resources for further reading).

Box 4.1 Useful resources available for early intervention services

• Dementia Revealed: What Primary Care Needs to Know. A Primer for General Practice

www.england.nhs.uk/wp-content/uploads/2014/09/dementia-revealed-toolkit.pdf An educational tool for general practitioners and practice nurses who have no experience in diagnosing and treating dementia prepared in partnership with NHS England and Hardwick CCG with the support of the Department of Health and the Royal College of General Practitioners in the UK. It covers topics such as identification and diagnosis of dementia, assessing cognition, ADL, brain scans, when to refer, drugs and other treatment, social services, and carers' assessment.

Dementia Toolkit for Primary Care, Sinai Health
 www.mountsinai.on.ca/care/psych/patient-programs/geriatric-psychiatry/prc dementia-resources-for-primary-care/dementia-toolkit-for-primary-care
 A toolkit and resources specifically designed for primary care with documents available
 for downloading from Mount Sinai Hospital in Canada. Covers assessment and
 screening tools, diagnosis of dementia, delirium, medication management, depression,
 responsive behaviours in dementia, driving safety, carer support, and palliative care.
 Dementia Outcomer Macrument Suite (DOMS)

Dementia Outcomes Measurement Suite (DOMS) https://dementiaresearch.org.au/doms/ A compendium of validated tools for the assessment of various aspects of dementia. A user-friendly website focused on clinical practice covering different types of dementia, severities of impairment, clinical settings (including primary care), and assessment modalities. Dementia outcome measures reviewed on this website may be used to screen for dementia signs and symptoms, monitor progression and treatment effects, and facilitate service planning. Updated web links and directories to many tools recommended in this chapter (e.g., Clinical Dementia Rating and Functional Assessment Staging Test) can be found in DOMS.

4.1 A Sample Form to Facilitate History-Taking

Box 4.2 shows a sample form to facilitate the recording of essential information during a help-seeking or first consultation with the primary care team.

The information included in this sample form is essential for the following reasons.

Age

Dementia is an age-related disease, with its age-specific prevalence ranging from 2 per cent to 41 per cent across countries in people aged 65 years or above (3). Finding out the age of the person with suspected dementia therefore provides some information about the likelihood of a person having dementia:

- 65-69 years old: 2 per cent
- 70-74 years old: 4 per cent
- 75-79 years old: 7 per cent
- 80–84 years old: 12 per cent
- 85–89 years old: 20 per cent
- 90+ years old: 41 per cent

For young-onset dementia (defined as onset before age 65), the estimated prevalence ranges between 42 and 98 per 100,000 people (4).

Education

Education forms an important part of the history because of its role as the main proxy for cognitive reserve (5, 6). A higher education level is associated with a lower risk of developing dementia (7). According to the cognitive reserve theory (8), for a person with a higher education level (thus reserve) to present with a functional impairment that exceeds the clinical threshold, s/he will have to sustain a bigger lesion compared with someone with a lower education. Likewise, a person with a higher reserve presenting with mild Alzheimer's disease symptoms would have more severe underlying pathology compared with someone presenting with a similar symptom level but a lower reserve. Education thus provides estimates about the severity of brain pathology given similar presentations. Education also significantly impacts cognitive assessment performance (see Section 4.3), and years of education is needed to interpret these test results.

Occupational Attainment

Like education, occupation is also a major proxy for cognitive reserve (5, 6). Thus, the above comments regarding symptoms/impairment presentation and underlying pathology also apply to the person's work history, specifically work complexity and occupational attainment.

Marital Status, Living Arrangements, and Relationship with the Informant

Marital status, living arrangements, and relationship with the informant are needed for a quick assessment of the person's support and safety in community living. Understanding the living arrangements and the person's relationships would provide information about a knowledgeable informant's and potential carers' stress and burden.

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	r other treatment? Specify:						

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Key Complaints (Open-Ended)

The open-ended method is an unstructured/unprompted way to capture spontaneous complaints. The type and pervasiveness of symptoms that informants report spontaneously predict the clinical severity (9). This may provide a quick reference for triage (see Section 4.4).

Interview with Informant (Modified from GPCOG)

The General Practitioner Assessment of Cognition (GPCOG) was designed as a brief and efficient screening tool for dementia for use in primary care (2). The rationale for developing the tool was due to the great need to detect and diagnose dementia by primary care physicians or general practitioners, which was not satisfactorily addressed by existing screening tests. The original GPCOG consists of items for cognitive tests and history-taking with the informant. Included in this sample form is only the informant's history-taking part; as we recommend in a multidisciplinary primary care team setting for early intervention in dementia, cognitive tests can be performed by trained allied health and social care professionals, with results shared within the team (see Section 4.3). The informant section of GPCOG was also found to be free of bias due to age, education, or depressive mood (10). Note that in the item about using transport, a remark is added to differentiate difficulties not due to cognitive but physical problems.

Delusions

Delusions are generally defined as fixed beliefs that are incorrigible despite conflicting evidence (11). They are key neuropsychiatric symptoms in dementia or neuropsychiatric symptoms (see Section 4.4 for examples). A common presentation of delusion in dementia is the person insisting that others are trying to steal from him/her (12). Exploring the presence of delusions can be helpful in screening, staging, and prioritising management, as they are often a trigger for help-seeking and a source of stress for the family, while their episodic nature provides anchors for estimating the time frame.

Family and Personal History

These would include current and past histories of psychiatric illness and physical health problems (such as stroke and head injury), recent hospitalisation, sensory problems, and alcohol and drug use.

Clinical Features Suggestive of Non-Alzheimer's Dementia

Apart from the above basic information on history-taking, the primary care team should pay attention to some of the following commonly reported clinical features that may suggest non-Alzheimer's dementia (see Box 4.3).¹

¹ For more detailed discussions about clinical features of common non-Alzheimer's dementia, readers may refer to textbooks or review articles, such as the series 'Non-Alzheimer's dementia' from The Lancet (13), or an introduction to the common dementias in resources such as the Promoting Psychological Wellbeing for People with Dementia and Their Carers: An Enhanced Practice Resource (14), for health and social care staff.

	 ier 5 dementia
Feature	Consider possible
Complex visual hallucinations	DLB, PDD
 Apraxia in self-care (e.g., inability to get dressed or use feeding utensils) 	CBD
Pain and rigidity on one side	CBD
Inability to control mood and aggression	bvFTD
Overeating, especially sweet food	bvFTD
 Early speech problems without evidence of stroke or SOL 	PPA/tvFTD
Early swallowing problem	PSP
SOL = space-occupying lesion; DLB = dementia with Lewy l disease dementia; CBD = corticobasal degeneration; bvFTD	

frontotemporal dementia; PPA = primary progressive aphasia; tvFTD = temporal variant of frontotemporal dementia; PSP = progressive supranuclear palsy

Box 4.3 Additional clinical features to consider for non-Alzheimer's dementia

Complex Visual Hallucinations

Visual hallucination is the clinical feature that most specifically distinguishes Lewy body from Alzheimer's disease in early-stage dementia (15). In dementia with Lewy body, as compared to Alzheimer's disease, the visual hallucinations are more likely to be multiple, speaking, and persistent (16). The core features of dementia with Lewy bodies (DLB) include fluctuating levels of attention and alertness, well-formed and detailed recurrent visual hallucinations, which are generally present in the early course of the disease, and spontaneous features of parkinsonism, such as bradykinesia and rigidity (17, 18). As Parkinson's disease dementia (PDD) and DLB have overlapping features and similar hallucination characteristics (19), PDD should also be considered. Another telltale symptom is the presence of rapid eye movement (REM) behaviour disorder (RBD), which could precede the dementia symptoms by some years (20). In clinical settings, people with DLB may have hallucinations preceded by hospitalisation, in the form of delirium, which may be understood as an overflow of dream content into the consciousness and experienced as hallucinations.

Apraxia in Self-care

Deficits in basic self-care (such as getting dressed) are a feature in the moderate rather than early stages of Alzheimer's disease (21). Apraxia in self-care is, however, a feature that can be seen in both progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD) and is more severe in the latter (22). Thus, in a person presenting with apraxia in self-care with assessment findings suggestive of early dementia, non-Alzheimer's dementia such as CBD should be considered.

Pain and Rigidity on One Side

Apart from apraxia in self-care, asymmetric stiffness or rigidity and pain are other common features of CBD (23), with limb clumsiness and tremors commonly observed before unilateral limb rigidity.

Inability to Control Mood and Aggression

Mood and anxiety symptoms can be present in early Alzheimer's disease, which may increase as the disease progresses (24). However, excessive mood swings and aggressive behaviour are uncommon in the early stages of Alzheimer's disease, but may represent features of behavioural variants of frontotemporal dementia (bvFTD) (25), which is characterised by personality changes, behavioural disinhibition, and apathy.

Box 4.4 Variants of FTD

Frontotemporal dementia can be further classified into the following:

- behavioural variant frontotemporal dementia (bvFTD);
- non-fluent variant primary progressive aphasia (nfvPPA);
- semantic-variant primary progressive aphasia (svPPA).

Overeating, especially sweet foods

Binge eating and a preference for sweet foods are common features of bvFTD, which may be seen in 25 per cent to over 80 per cent of people with bvFTD (25). Disinhibition of impulse and basic needs control can be understood by frontal and executive dysfunction, which could also manifest as sexual disinhibition, poor hygiene, and early incontinence. In early dementia, especially in those presenting at a younger age (e.g., in their 50s or 60s), non-Alzheimer's dementia involving frontal lobe pathology should be considered.

Early speech problems without evidence of stroke or space-occupying lesion (SOL)

Speech problems are usually present in the advanced stage of Alzheimer's disease (21). If speech problems are present early – dementia with early speech involvement – primary progressive aphasia (PPA) or temporal variant FTD (tvFTD) should be considered (25).

Early swallowing problem

Swallowing problems occur very late in Alzheimer's disease (21). The presence of an early swallowing problem and parkinsonism suggests possible progressive supranuclear palsy (PSP). Other presentations of PSP include gaze palsy and postural instability (26).

Box 4.5 The non-Alzheimer's dementias

Belonging to one group of disorders with similar pathology, FTD, PPA, PSP, and CBD have varying symptoms. Put in a simplified way, they are characterised as follows:

- FTD: behaviour- and speech-related symptoms;
- PPA: speech-related symptoms;
- PSP: gaze- and swallow-related symptoms;
- CBD: apraxia symptoms.

As these dementias may evolve into a secondary diagnosis, a referral to secondary and tertiary care is needed.

Box 4.6 Midlife and later-life risk factors for dementia

Midlife

- □ Hearing loss
- □ Traumatic brain injury
- □ Hypertension
- □ Alcohol (>21 units per week)
- □ Obesity

- Later life
- Depression
- □ Social isolation
- □ Physical inactivity
- □ Air pollution
 - □ Diabetes

Other Information to Consider Collecting

Apart from 'passive' cognitive reserve (with education level and occupation attainment as proxy) covered above, understanding other known and modifiable risk factors would also provide information about the likelihood of neuropathological damage (e.g., vascular or inflammatory) and the potential of increasing 'active' cognitive reserve (e.g., increasing social contact) (7). Box 4.6 (based on (7)) lists the key risk factors in midlife and later life. In areas where driving is an important aspect of daily life, information about the person's current driving habits is also needed for an assessment of safety. For care planning, assessing family structure, relationships, and other support networks would be useful.

4.2 Physical Examination and Investigation Checklist for Suspected dementia

Box 4.7 shows a suggested order for relevant investigations for suspected dementia. For specific recommendations of tests and examinations, please refer to locally relevant clinical guidelines, such as the UK National Institute for Health and Care Excellence (NICE) guidance on Dementia: Assessment, management and support for people living with dementia and their carers (27). Briefly, in non-specialist settings, blood and other tests are undertaken to exclude reversible causes of cognitive impairments. Further tests such as fluorodeoxyglucose-positron emission tomography-computed tomography (FDG-PET-CT) should be considered only if they would facilitate dementia subtyping and the subtype would inform management. Primary care physicians should note that tests and brain imaging results are only for reference to guide clinical judgement. For example:

- Findings of vitamin B₁₂ deficiency do not necessarily mean vitamin B₁₂ deficiency is the cause of dementia symptoms.
- Alzheimer's disease should not be ruled out based solely on CT or MRI findings.
- Vascular dementia cannot be diagnosed based solely on vascular lesion burden.

4.3 Sample Cognitive and Functioning Report of an Early Intervention Service

Box 4.8 shows a sample brief report for quick communication of the cognitive and functioning assessment findings within the primary care team. Whenever possible,

Box 4.7 Checklist of investigations for the primary care physician to consider

the detailed assessment results should be included as appendices as part of the service record.

Cognitive Functioning

For early detection services, quick cognitive screening tests are needed with good psychometric properties, validated in normative samples locally (to understand 'normal' performance in a population), with good sensitivity and specificity in detecting cognitive impairment across the spectrum of mild cognitive impairment, early Alzheimer's disease, and other dementias (such as post-stroke cognitive impairment). They also need to be easy to administer by trained personnel across disciplines to allow for scaled-up services and communication.

Traditionally, the Mini-Mental State Examination (MMSE) (28) is one of the commonly used tools for these reasons. The Montreal Cognitive Assessment (MoCA; see www.mocatest.org/) is another popular tool (29). They are therefore included in this sample report form, although the selection of tests should also take into consideration the service context (e.g., level of specialisation and care pathway) and other local factors. In reporting, the following should be noted:

Education level

Scores for both MMSE and MoCA need to be adjusted for the education level (30). Especially with MoCA, very different cut-off scores have been reported for people with different education levels (31), and in some populations, a single cut-off was

Seen by			with informant (relationship)		
Cognitive functioning	Assessment MMSE MoCA	Score /30		Remarks	
	CDT	_ / 10			
	Others				
ADL/IADL	BI	/100			
	51				
	Lawton	_/56			
	Others				
Depressive symptoms	GDS-15	/15			
	PHQ-9	_/27			
	Others				
Staging & clinical rating	GDS	Stage			
	CDR	_/3			
	Others				

found to risk misclassification (32). In the report, include a locally validated cut-off if available and always explain whether the score has been adjusted for the person's education level.

• Performance by cognitive domains As illustrated in Chapters 2 and 3, impairment pattern by cognitive domains provides important information about possible Alzheimer's disease, other dementias, and conditions (33) and for tailoring care and intervention strategies. Reporting only the total score with a cut-off – a binary approach to cognitive impairment – means losing useful information that would be useful for triage and service planning. Reporting the domain scores is therefore recommended in the report. As age-related changes are not uniform across cognitive domains (34), ideally, neuropsychological assessments with population-specific normative cut-offs by domain (35) would give more accurate information, although time and test burden should be considered. Brief screening assessments that emphasise domain profiling, such as the Oxford Cognitive Screen-Plus (OCS-Plus) (36, 37), can be considered to address this need.

• Details that are remarkable

The assessor will often observe details in the process that can facilitate results interpretation. For example, the person's understanding of the assessment may be affected by language, mobility, mood, and physical discomfort. Was s/he motivated and cooperative in the assessment? Were there noticeable cognitive impairments during the test (e.g., difficulty remembering the instructions, or easily distracted)? Some of the screening tools (e.g., MoCA) include items that are not scored but contain useful information about the person's cognitive performance, such as delayed recall with cues or by recognition, which suggests whether information storage is intact by testing if performance is improved by reducing retrieval demands.

The Clock Drawing Test is another widely used test in clinical practice and research. In some of the screening tools, such as MoCA, a simplified version of clock drawing is incorporated as part of the test. It should be noted that many studies compared head-to-head copying and drawing under instructions (38, 39) and found that clock drawing under the instruction condition is more challenging than the copying condition and is thus more sensitive to early changes in cognitive functioning.

ADL/IADL

A commonly used tool for assessing activities of daily living (ADL) is the Barthel Index (40), which consists of 11 items on basic self-care tasks such as feeding, toileting, and bathing (score range, 0–100). For instrumental activities of daily living (IADL), the Lawton's IADL Scale (41) can be used, which consists of eight self-care items required for independent community living, such as meal preparation, handling finance, and housekeeping. These are tools often used in other aged care services/ geriatric medicine fields, allowing for easy communication across services, and are therefore useful in dementia screening and early detection services. Tools that provide ADL/IADL information specific to dementia include the Alzheimer's Disease Cooperative Study – Activities of Daily Living Scale (ADCS-ADL) (42) and the Disability Assessment for Dementia (DAD) (43).

Communicating information about the person's ADL and IADL functioning within the primary care team will be useful for diagnostic, staging, and care/intervention planning purposes. For the latter, based on the biopsychosocial model of dementia (44), such information could be used to guide the identification of excess disability and tractable factors to intervene (see Section 1.5). When reporting, it would be helpful to remark whether the ADL/IADL impairment is likely due to physical frailty/medical conditions other than cognitive impairment.

Depressive Symptoms

Clinically significant depressive symptoms are prevalent among older people (approximately 10 per cent to 15 per cent, depending on settings) (45) and can complicate diagnosis, care, and intervention, as illustrated in previous chapters. Routine screening for depressive symptoms is therefore recommended among those seeking help for suspected dementia. The 15-item Geriatric Depression Scale (GDS) (46) is commonly used in geriatrics/aged care in view of its sensitivity and specificity in identifying depression in older people (a cut-off score of 8 out of 15 indicates clinically significant depressive symptoms). Other assessment tools not specific to older people that are also useful include the Patient Health Questionnaire (PHQ-9) (45), a nine-item tool that incorporates depression diagnostic criteria into the items, thereby also providing information about the presence and severity of individual depressive symptoms.

Staging and Clinical Rating

This part of the assessment would require interviewing with a knowledgeable informant. The Clinical Dementia Rating (CDR) (47) is a structured interview schedule involving both the person with suspected dementia and an informant to estimate performance in memory, orientation, judgement and problem-solving, community affairs, home and hobbies, and personal care (see https://knightadrc.wustl.edu/cdr/cdr.htm for details about training, scoring, and versions). It has a global rating ranging from 0 (normal) to 5 (severe dementia). The Global Deterioration Scale (GDS) (48) is a widely used scale to reflect the clinical characteristics of dementia, with stages 1–3 denoting pre-dementia stages and stages 4–7 denoting dementia stages. For a more specific staging assessment, the Functional Assessment Staging (FAST) in Alzheimer's Disease (21, 49) can be considered (see Section 1.3).

4.4 Common Symptoms Reported by Carers and People with Suspected Dementia

In Section 4.1, a sample form to facilitate history-taking in an unstructured, open-ended way to capture spontaneous complaints is suggested. This is considering the help-seeking population in an early intervention service setting, in which symptoms that have prompted help-seeking have clinical significance (as compared with symptoms elicited in structured interviews). The type of symptoms noted by an informant and the number of symptoms noted in these simple open-ended questions are linked with the clinical stage assessed using CDR (9), thus providing a quick indicator for triage and further investigations. These spontaneously reported symptoms can be grouped into categories as suggested in Box 4.9.

While memory problems are frequently reported, they are less discriminating as compared to language and orientation symptoms noted by an informant (9). The number of symptom categories spontaneously reported by the informant would also suggest more severe dementia when assessed in a more structured way (e.g., using CDR).

Symptom	Examples
Memory	'he only remembers things that happened a long time ago'
Executive function	'she cannot manage to cook any more'
Language	'sometimes I cannot understand what she is trying to say'
Orientation	'he was unable to find the way from home to a nearby restaurant'
Neuropsychiatric	'he is always paranoid'
□ Mood	'she always talks about sad things'
Avolition	'she has decreased motivation in participating in leisure activities'

Box 4.9 Classification of common spontaneously reported symptoms from an early intervention service (9)

4.5 Infographic and Educational Material for Explaining Dementia Diagnosis and Management

Apart from the widely known resource centres such as Alzheimer's Disease International (ADI, www.alzint.org/), Dementia Alliance International (DAI, www.dementiaalliancei nternational.org/), and the Alzheimer's Association (www.alz.org/), various educational materials and helpful infographics have been developed and are available online. Box 4.10 lists a few useful examples that can be incorporated into a primary care practice for dementia early intervention.

Box 4.10 Some useful infographics and educational material for use in primary care

• Visual summary of updated NICE guidance Dementia: assessment, management and support

www.bmj.com/content/bmj/suppl/2018/06/27/bmj.k2438.DC1/Dementia_v19_web.pdf This plain language summary (50) available from *The BMJ* includes a one-page visual summary on pharmacological treatment – donepezil, galantamine, rivastigmine, and memantine – that can be offered as part of the management of Alzheimer's and other dementias according to disease stage, tolerance, and existing medications.

Dementia infographic by the US National Institute of Aging
www.nia.nih.gov/research/alzheimers-dementia-outreach-recruitment-engagementresources/dementia-infographics-madrc
Single-page infographics covering various topics in Alzheimer's disease and related
dementias were developed by the Michigan Alzheimer's Disease Research Center
(MADRC) for free download. Resources available include infographics explaining the
difference between Alzheimer's disease and other dementia types, and whether
Alzheimer's disease is genetic.
 World Health Organization (WHO) Infographic on Dementia

www.who.int/health-topics/dementia#tab=tab_1 A simple two-page infographic explaining the symptoms of dementia, its causes, and the number of people affected. It also provides information about the global action plan and highlights dementia as a public health priority.

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